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RESPITE CARE: A SURVIVAL TECHNIQUE FOR FAMILIES OF CHILDREN WITH SEVERE HANDICAPS

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ABSTRACT

Respite care for children with severe handicaps and their families has been developed to serve the rural, sparsely populated areas of up-state Wisconsin. A variety of options made available through Federal Child Welfare Grants to parents of the highly dependent child to "revitalize" themselves to deal with their child's daily needs have proven successful. Since its' inception in October, 1976, the program has provided a necessary outlet to the families of 51 children who used respite for 391 days. Currently, the cost for providing comprehensive 24 hour care for each child is $1.45 per hour or $34.70 per day (approximately $12,492 per year) although parents are only asked to pay $8 or $10 per day for non-ambulatory or ambulatory children respectively. Compared to current residential and hospital fees for the same service which exceed $20,000 to $30,000 per year, respite is quite cost/effective. The basic elements of the program are easily definable and lend themselves to being replicated throughout the country and/or across other nations. To demonstrate the duplication potential of respite care, four (4) Regional replication workshops were held at different locations in the State for 80 persons from a variety of local, state, regional and private agencies to train them to develop additional respite care sites.

Respite is defined by Webster (1968 Edition) as "an interval of temporary relief or rest, as from pain, work, duty, etc." Oftentimes the family of an extremely handicapped member could benefit from a temporary rest away from the day-in, day-out dependent care requirements. In fact, it is believed that by providing respite opportunities to the family, a revitalization will occur thus inspiring a fresh outlook for the continued care of their dependent member.

Although there appears to be a need for respite care across the nation, only sporadic program development has occurred as noted by Shoof (1977). Shoof's data illustrates a general, non-standard approach to program development, organization and financing since a variety of agencies appear to be involved without a clear indication being given to who is responsible to maintain quality assurance. A variety of programs have made considerable impact on mild and fairly manageable handicapped children, i.e. the Hartford Connecticut Regional Respite Center, 1973, and Childrens Service Incorporated of Philadelphia, Pennsylvania in 1976. However, respite care alternatives for severely handicapped children who often have medical needs have been lacking if not totally missing outside of residential institutions and hospital settings.

WHY RESPITE CARE FOR CHILDREN WITH SEVERE HANDICAPS?

The child with severe handicaps represents a complex situation for its' family in general, since he requires much attention from all family members. And more specifically, the parents of the family are often under a great deal of stress when it comes to dealing with the child's daily needs. Special attentions required by this highly dependent child include intensive day round care or supervision; individualized feeding considerations (nasogastric, intravenous, etc.); and, technical care

requirements (gavage, postural drainage, respiration, chemical discrimination diets, physical/occupational therapy activities, etc.). In addition, this child often has complex medical needs (multiple medications, epilepsy, and/or prosthetic/orthotic requirements). Other considerations include management procedures for the hyperkinetic, emotionally disturbed, physically disabled or otherwise severely impaired child. Respite care for the severely handicapped child necessitates pre-placement planning considerations that must take into account pnysical, emotional as well as medical needs.

At the Marshfield Comprehensive Child Care Center respite care has become known as "a preventive service to minimize chances of long term residential placement and, reduce the possibility of family disintegration due to the effects of having a severely handicapped member." Initiated in October, 1976, Ptacek, Sommers, Lukowicz et.al., 1977, indicate that the Marshfield program offers any family of a severely handicapped child (from birth to age 18) with time away to revitalize. Options have been identified on at least four levels:

(1) While family is on vacation

(2) For a few days at a time during the week

(3) A weekend or two a month

(4) On an emergency basis

A child may be placed into respite care for a minimum of two (2) consecutive days and a maximum of fifteen (15) consecutive days. Respite care can be used by the same child as often as necessary. A determination of the length of each placement is made in advance except in those cases arising on an emergency basis. At the time of discharge, a written review of the child's performance (physical and behavioral) is made by the respite care foster parents. This report is an account of daily

happenings reflective of the type of care needed and provided; and, any other significant information that when considered by the child's legal parents, would help to improve his well-being and development.

ADMISSION PROCESS

Referrals are accepted from any source and are coordinated through the Comprehensive Child Care Center and Wood County Social Services located in Marshfield, Wisconsin. After receiving the referral, a basic set of procedures is rapidly completed to finalize the admittance procedure. Following acceptance of the referred child, a date and time is set for placement into respite care. The parents must bring any special supplies and equipment, i.e. braces, medications, etc. along to the respite home.

SUPPORT SERVICES

Wood County Department of Social Services, the Regional Division of Community Services in conjunction with the Comprehensive Child Care Center provided the basic planning and development support for the program. Since oftentimes the severely handicapped are in need of medical considerations, arrangements have been made to provide appropriate care with staff of the Marshfield Clinic and St. Joseph's Hospital which are located near the homes. Verbal agreements exist between the respite care foster parents and local druggists to insure 24 hour service for necessary medications and supplies. Currently, the homes of two (2) families living in the Marshfield community serve as the physical facilities. Each home has two (2) beds available for children. The program was designed so that each home would function on a "one-half time occupancy basis" (15 days of placement per bed per month). This situation allows one home to serve as a back-up to the other. In addition, placements are staggered to provide an interval of free time between placements for the respite

foster care parents to handle their routine needs in preparation for the next placement.

LICENSURE, FINANCING AND COSTS

The Wood County Department of Social Services has licensed the homes through its' regular procedure used for foster homes but specifically as respite care facilities (in accordance with Rules for Licensing Foster Homes in the State of Wisconsin). The respite care parents have families of their own and are extremely interested in helping handicapped children. A background of experience and training in the area of child care is a prerequisite qualification for becoming a respite foster care parent. Nurses training and related experience have proved to be valuable assets for the respite care foster parents. Without question, a most important consideration when developing a respite care program is the selection of respite foster care parents.

Initial funding to establish the program was provided by Federal Child Welfare Funds beginning in October of 1976. A monthly subsidy of $220 per bed ($440 per home per month) is paid each respite care foster family. Per diem finances for daily board and lodging expenses are also paid. If the child's parents can not afford to pay the per diem rate of $8.00 for a non-ambulatory child or $10.00 for an ambulatory child, county, state or regional resources are available to help the family with this payment (there are also monies available in the grant to help offset these costs through the remainder of the project year which ends September 30, 1978). Plans are made for the Wood County Department of Social Services to take over the financial responsibility for subsidy payments when the Federal Child Welfare Funds expire. Placement statistics developed from the inception of the program through its' nineteenth month (October 1, 1976 through April 30, 1978)

indicate that 51 children have used the program accounting for 391 days of placement. To date, a cost/utilization rate of $34.70 per day ($1.45 per hour for a 24 hour period) exists. This rate calculated over a thirty (30) day period is equivalent to a monthly amount of $1,041 which equates to a yearly approximation of $12,492. These figures are based upon total expenditures minus fees paid (per diem costs paid by families using the home) of $13,568.46. Included within this total are subsidy costs; start-up expenses; equipment; and, ongoing supply costs. This total does not reflect agency staff time nor other in-kind contributions.

HAS THE PROGRAM BEEN SUCCESSFUL?

Conjecture would have it that the program has been good because it serves severely handicapped children and their families who might not have the opportunity for relief without such an effort. Perhaps one might look at the problematic geographical factors involved since all children served are from basically rural, non-urban areas in Central and Northern Wisconsin where comprehensive resources for this type of a need have just not been available. It is important to note that the program began at the "grass roots level" and flourishes through an interaction of interested local child service organizations because it is a cooperative venture. Although these subjective statements are accurate, they only represent qualitatively based points of view.

Objectively based evaluation data has been gathered through the utilization of a follow-up questionnaire survey which was designed to examine the satisfaction parents and referring case coordinators have with the respite care. A critical analysis was made of each program element and questions were developed to assess the level of satisfaction each respondent (parent and case coordinator i.e. the case coordinator is

usually the individual referring the family to the program) had with each important aspect. Each respondent was asked to rate the questions corresponding to their level of satisfaction with the respite service received particularly as they related on a basic yes (positive) or no (negative) continuum. Since much essential information could not be obtained from either a yes or no response the yes-no continuum was expanded to include a rating of satisfaction scale ranging from 0 to 100 per cent, with a rating of 50 being average.‡

The mean average level of satisfaction calculated for each question can be interpreted as a rating of "efficiency" i.e. how competently is respite care being provided? By using this method, it is possible to assess how well each aspect of respite care is being received and, more importantly, data is obtained which reflects those specific program elements in need of improvement or modification to better meet the needs of each involved child and family.

RESULTS

The evaluation questionnaires described above are routinely sent to each parent and case coordinator. The questions are different for each group. A cover letter explaining the procedure accompanies each questionnaire. 51 children have been placed into respite care from October 1, 1976 through April 30, 1978 (8 children used respite more than once). Children have come from eleven different Central and Northern Wisconsin counties. Four times as many children (16) came from Wood County which is where the respite homes are located. Up to the time of this report questionnaires had been sent to approximately half of the families who used respite care (24 families had used respite care between October 1976 through December 1977). The following findings will reflect upon the ratings obtained from the first 24 children placed into the program.

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‡ Contact author for further information

Parents

23 of the 24 parents (96%) returned their questionnaire. Table 1 reflects the questions asked each parent and includes the mean average rating. Respite care was used for vacations, weekends and was scheduled at times to give parents a few days rest as well as in emergency situations. 95% of the parents did not have any difficulties scheduling their respite care and 78% indicated that they would be interested in using the program again. 78% of the families using the program live within 100 miles of Marshfield.

(INSERT TABLE 1 ABOUT HERE)

Case Coordinators

8 of 8 case coordinators referring children to the program returned their questionnaires (the remainder of children who used the program were referred by their families). All but one of the case coordinators (a developmental disability staff member) were social workers for either a county or Regional Division of Community Service Center. Table 2 illustrates the questions and includes mean average ratings of satisfaction. One of the Regional Division of Community Service workers made five separate referrals (the remainder of case coordinators made 1 referral each). None of the case coordinators had trouble scheduling respite, and all indicated an interest in using the program again. 88% live within 100 miles of Marshfield.

(INSERT TABLE 2 ABOUT HERE)

Open ended comments and suggestions about the program were encouraged and received from both parents and case coordinators. These suggestions have been reviewed by staff and where appropriate, incorporated to improve program operations.

Table 1

Parent Rating Display

Questions	# Responding	Mean Average Percentage Rating of Satisfaction
1. Did the Respite Care Program meet the needs of your child?	22	84
2. Do you feel comfortable in leaving your child in the Respite Care Home?	22	84
3. Do you feel it would be beneficial to visit the home prior to leaving your child there?	23	80
4. Were the Respite Care Parents warm and receptive to your child?	23	92
5. Do you feel that your child benefitted from the Respite Care?	22	75
6. Do you feel that the cost is reasonable?	23	91
7. Did you receive helpful information from the Respite Care Parents on the care of your child?	22	67
8. Did the Respite Care Program meet with your expectations?	21	83
10. Were you pleased with the overall care provided at the Respite Care Home?	22	88

Table 2

Case Coordinator Rating Display

Questions	# Responding	Mean Average Percentage Rating of Satisfaction
1. Were the parents satisfied with the care of their child?	8	86
2. Did the parents receive helpful suggestions and support in the care of their child from the Respite Care Parents?	8	76
3. Do you feel that the parents benefitted from the Respite Care?	8	100
4. Did the Respite Placement meet with your expectations?	8	89
5. Do you feel it would be beneficial to visit the homes before recommending them to parents for placement of their child?	8	66
6. Do you feel that the cost is reasonable?	8	88
8. Do you feel that the child benefitted from the Respite Care?	8	79
10. Were you pleased with the overall care provided at the Respite Care Home?	8	94

REPLICATION

The program proved to be successful as a survival technique for families of children with severe handicaps. A quote from one of the parents reflects the general spirit of responses:

> "This program literally saved my marriage, my sanity and probably my little boy's sanity too - Thank God someone out there cares..."

Based upon this success, a training project was developed and funded by the Wisconsin State Department of Health and Social Services through Title XX revenue. This project proposed that at least 50 persons would receive training to develop their own respite care programs throughout the state. Four (4) locations across the state served as training sites and eighty (80) individuals participated.

Training activities focused on "ways and means" to initiate respite care. All aspects of program development were covered through the activities presented and included: needs assessment strategies; referral and intake procedures; behavior management techniques; interagency cooperation; funding and licensing homes; recruiting and screening potential respite care parents; and, developing and implementing program evaluation systems. Additionally, representatives from two other model state respite programs joined staff from the Comprehensive Child Care Center for the duration of the training activity. These individuals currently operate successful respite programs in other parts of the state which deal with developmentally disabled adults; the mentally ill; elderly; terminally ill; and, mothers of dependent children. The 80 participants who received the training highly rated their experiences and complete evaluations were made of each workshop conducted (a complete report of training workshop evaluation data can be obtained by contacting the author).

CONCLUSION

Respite care has demonstrated to be an excellent method of family intervention by providing intervals of relief for both parents and children with severe handicaps. At a cost far less than currently required for basic residential and/or hospital facilities (state figures indicate that it costs from $20,000 - $30,000 per year per child for state respite care whereas, respite care costs for purposes of this report are about one-half that amount), respite care options can fit into almost any budget. In addition, each severely handicapped child becomes a member of the foster respite family in a home setting. This factor was highly rated by referring parents and case coordinators since they preferred such an option to the hospital/residential environment. Being relatively easy to understand, uncomplicated to organize and suited for replication, respite care program development will certainly be able to help handicapped individuals throughout the world.

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